Perceived discrimination against cured cancer patients in the work force

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To evaluate perceived discrimination against cured cancer patients in the work force in Montreal, in 1982–83 we surveyed 101 cured cancer patients and 101 control subjects who had never had cancer and who were matched for age, sex and neighbourhood of residence. In addition, 24 of the cured patients were randomly selected and paired with cancer patients with a poor prognosis who were matched for age and sex. Discrimination was slightly more common among cured patients (18%) than among control subjects (15%), and 21% of the cancer patients with a poor prognosis reported discrimination. Analysis of the comparisons between the cured and control groups indicated no statistically significant differences. The cured cancer patients reported the following problems faced by cancer patients returning to work: fatigue (30%), absenteeism (14%), psychologic problems (12%), social stigma (12%) and discrimination by an employer (10%).

Pour évaluer le degré de discrimination dont les patients guéris du cancer dans la population active à Montréal se sentent l'objet, on a interrogé, en 1982–83, 101 patients guéris du cancer et 101 sujets de contrôle jamais atteints du cancer. Ces groupes ont été appariés en fonction de l'âge, du sexe et du lieu de résidence. De plus, après avoir choisi au hasard 24 des patients guéris du cancer, on les a appariés à des patients atteints du cancer avec pronostic mauvais, en fonction de l'âge et du sexe. La discrimination était légèrement plus répandue contre les patients guéris (18%) que contre les sujets de contrôle (15%); 21% des patients atteints du cancer avec pronostic mauvais ont fait état de discrimination. Aucune différence statistiquement importante n'est ressortie de l'analyse comparative des résultats pour les groupes guéris et de contrôle. Selon les guéris du cancer, les personnes atteintes du cancer retournant au travail ont les problèmes suivants: fatigue (30%), absentéisme (14%), problèmes psychologiques (12%), stigmatisation sociale (12%) et discrimination par l'employeur (10%).

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With longer survival of cancer patients, increasing emphasis has been placed on the quality of survival. Resumption of employment or other meaningful activities has been considered an important aspect of good quality of life.[1] In one study cancer patients who were working had significantly higher scores for morale and well-being and lower anxiety measures than those who were not employed.[2] Discrimination against cured cancer patients by employers or prospective employers would impede return to the work force and thus diminish the quality of survival.

Employers' fears of high rates of absenteeism and poor work performance are thought to be the main reasons for discrimination against cured cancer patients.[3] Recent research has shown that these fears are not well founded: recovered cancer patients compare favourably with employees who

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have not had cancer, both in attendance and in work performance.[3-5]

The American Cancer Society has estimated that approximately 90% of cancer patients who try to re-enter the work force are confronted with discrimination.[6] A study in California of 100 blue-collar workers cured of cancer revealed that 35% had perceived discrimination, 13% had been denied work specifically because of their health history and 11% had been excluded from group health insurance programs.[7] Another US survey indicated that 25% of cured cancer patients had encountered discrimination, and 12% had been denied health insurance benefits.[3]

Although there are other studies that allude to the problem of discrimination against cured cancer patients, those by Feldman[7] and Reynolds[3] are the only two in the literature that are exclusively devoted to discrimination in the work place. Unfortunately, control group comparisons were not included in either study; thus, an "acceptable" degree of discrimination based on a standard for a comparison population could not be established. No such studies have been carried out in Canada, where health insurance and cost of care are not issues to employers or workers.

We undertook a study to determine whether cured cancer patients in Montreal encountered more discrimination in the work force than comparable subjects who had never had cancer. We also sought to determine what types of problems cancer patients face when they try to enter, re-enter or remain in the work force. Finally, we investigated whether cancer patients with a poor prognosis were confronted with more discrimination than those who were cured.

Methods

Subjects were eligible for inclusion in the cured group if they were between the ages of 21 and 65 years, had a working knowledge of English or French, had 5 years of disease-free survival with no current evidence of disease or were considered cured by their physicians, and lived in metropolitan Montreal. In addition, they had to have been working at the time of diagnosis, have looked for work since the diagnosis or be currently working. Subjects were eligible for inclusion in the control group if they matched a subject in the cured group with respect to age (within 5 years), sex and neighbourhood of residence, had a working knowledge of English or French and had never had cancer. In addition, they had to have worked for any length of time during the preceding 7 years, have looked for work in the preceding 7 years or be currently working. The time span of 7 years was chosen because this was the average time since diagnosis for the cured cancer patients. Subjects were eligible for inclusion in the poor prognosis group if they matched a subject in the cured group with respect to age (within 5 years) and sex, had a working knowledge of English or French and were judged to have a prognosis for survival of 1 year or less at the time of diagnosis. In addition, they had to have been working at the time of diagnosis, have worked since the diagnosis or be currently working.

From September to November 1982 the names, addresses and telephone numbers of all potentially eligible cured cancer patients in Montreal were gathered from hospital tumour registries or from the files of physicians affiliated with one of seven Montreal hospitals. The physicians were then furnished with a list of the names of their patients who met the inclusion criteria. Patients who were not considered suitable by their physicians were eliminated from the list of candidates. The remaining patients were then contacted. Those who agreed to participate were contacted by a trained interviewer and interviewed in their homes.

From January to March 1983, trained interviewers were given a list of the addresses, ages and sex of several of the cured cancer patients previously interviewed. The interviewers were instructed to locate the dwelling of the patient and to proceed to the right of the house, knocking on neighbouring doors in search of a person who matched the patient with respect to age (within 5 years) and sex. They were to proceed around the block until a suitable control subject was found. If the patient lived in an apartment building the interviewer was to begin on the floor directly above or below that of the patient. If unsuccessful after going around the block, the interviewer was instructed to repeat the procedure twice at different times. When these efforts failed to produce a suitable control subject the interviewer was to call for additional instructions. This occurred in 14 cases, and the interviewers were told to cross the street, where they eventually found appropriate subjects. The interviewers went to an average of 27 homes before finding a suitable control subject. Once a suitable subject was found, the interviewer explained the study and asked permission to administer a questionnaire.

One quarter of the cured cancer patients were randomly selected to be matched for age and sex with a cancer patient who had a poor prognosis. Physicians furnished with a list of the ages and sex of the patients in this subgroup supplied the names and telephone numbers of suitable patients, who were then contacted by a member of the research team. Those who agreed to participate were contacted by a trained interviewer and interviewed in their homes. This phase of the study was carried out during March and April 1983.

A 90-item employee questionnaire for the cured cancer patients was developed in English over a 3-month period specifically for this study. Fourteen people read and reviewed the questionnaire during its development. The questionnaire was subsequently revised and then administered as a pretest to 10 cured cancer patients who were not

included in the main sample but who met the eligibility criteria. Only minor revisions were necessary after the pretest, and the questionnaire was then translated into French. Translation back into English and pretesting of the French questionnaire proved it to be accurate and acceptable.

The questionnaire was also administered to the poor prognosis group. However, seven additional hypothetical questions on employment were asked of subjects who were neither working nor seeking work at the time of the interview but who had been working at the time of diagnosis.

The questionnaire was modified for administration to the control group. Nine people reviewed the questionnaire, and another nine were interviewed as a pretest. After minor revision the questionnaire was translated into French and then back into English to ensure accuracy of the French translation.

Verification questionnaires were formulated for the three study groups and were administered by telephone to a random sample of 10% of each group. These questionnaires contained questions about the interview (e.g., whether it had been a positive or a negative experience) and several questions from the original employee questionnaires to which the answers were unlikely to have changed between the times of the original interview and the verification interview. These questions served as measures of quality control and of test–retest reliability. For all three groups the rate of consistency of responses to these questions ranged from 92% to 100%. The quality-control measures indicated that the interviews were positive experiences and that the interviewers were pleasant.

Since the study had a matched design, we assessed differences between the cured and control groups by evaluating discordant pairs. The analysis was done separately for the two matched groups (cured–control and cured–poor prognosis). First, matching was checked to verify the comparability of the two groups with respect to such variables as education and bilingualism; the groups were found to be comparable. Second, comparisons between the two groups were evaluated with respect to willingness to inform a prospective employer of one's medical history, denial of standard benefits and other discrimination by an employer. We evaluated the cross-tabulations of matched pairs by calculating the Mantel–Haenszel odds ratio and the McNemar chi-square statistic for paired data. The composite outcome variable, discrimination, took into account a number of answers by each subject, including denial of a promotion, a raise, full health insurance benefits or a letter of recommendation (if requested) or being demoted or fired or not being hired for reasons associated with the medical history. The power of the study to detect an odds ratio of 2 for 101 pairs was 73% with α set at 0.05.

Table I—Types of cancer in 101 cured patients

Type of cancer	No. of subjects
Breast cancer	38
Hodgkin's disease	25
Testicular cancer	19
Lymphoma	9
Colorectal cancer	5
Other	5

Table II—Reported illnesses or conditions among 101 control subjects

Illness or condition	No. of subjects
None	45
Circulatory or cardiovascular	11
Musculoskeletal	9
Psychologic	8
Pulmonary	7
Other	21

Table III—Types of cancer in 24 patients with a poor prognosis

Type of cancer	No. (and %) of subjects
Breast cancer	11 (46)
Hodgkin's disease	2 (8)
Ovarian cancer	2 (8)
Other	9 (38)

Results

A total of 108 cured cancer patients were contacted, 7 of whom refused to participate; thus, the response rate was 94%. The 101 subjects in the cured group were matched with 101 control subjects. Of the 27 cancer patients with a poor prognosis who were contacted 3 (11%) refused to participate, because they felt too ill.

The mean ages (and standard deviation [SD]) at the time of interview for the cured, control and poor prognosis groups were 45.9 (12.0), 46.1 (12.6) and 45.3 (11.8) years respectively. There were 51 men and 50 women in both the cured group and the control group and 7 men and 17 women in the poor prognosis group. There were 55 francophones and 46 anglophones in both the cured group and the control group and 10 francophones and 14 anglophones in the poor prognosis group. The mean time lost from work since diagnosis (and SD) was 23.7 (22.5) weeks for the cured group and 7.9 (15.8) weeks for the control group. The types of cancer among the subjects in the cured group are shown in Table I. Of the control subjects 45 were classified as healthy because they reported having had no major disease in the preceding 7 years; the various illnesses or conditions reported by the other 56 are shown in Table II. Table III shows the

types of cancer among the subjects in the poor prognosis group.

Of the 101 cured cancer patients 18 claimed that they had been discriminated against by their employers or potential employers because of their cancer history, and of the 101 control subjects 15 perceived work-related discrimination because of medical problems. Five of the cancer patients with a poor prognosis (21%) felt that they had encountered discrimination in the work force. Denial of standard work benefits was claimed by 10 of the cured cancer patients, 8 of the control subjects and 5 (21%) of the cancer patients with a poor prognosis.

The cured cancer patients and those with a poor prognosis were asked to list the problems cancer patients face when returning to work. Both groups rated fatigue as the most important problem; discrimination ranked last for the cured patients and second for the poor prognosis group (Table IV).

No significant differences were found between the cured and control groups in willingness to reveal one's medical history to a prospective employer if asked, denial of standard work benefits or other discrimination by an employer (Table V).

Significantly more patients in the poor prognosis group than in the cured group reported that they would reveal their cancer history to a prospective employer if asked ($p = 0.008$) (Table VI). However, there were no significant differences between the two groups in denial of standard work benefits or work-related discrimination.

Table IV—Problems faced by cancer patients returning to work

Problem	Group; no. of subjects*	
	Cured	Poor prognosis
Fatigue	38	7
Absenteeism	18	2
Psychologic problems	15	5
Social stigma	15	4
Discrimination by employer	13	6
None	17	4

*Some subjects reported more than one problem.

Discussion

Two US studies revealed that 25%[3] and 35%[7] of former cancer patients encountered job-related discrimination. The rates in our study were 18% for cured cancer patients, 21% for cancer patients with a poor prognosis and 15% for control subjects who had never had cancer. Neither of the US studies had control subjects, which may explain the apparent discrepancies between the results. It is unclear whether our results reflect a less discriminatory attitude in Montreal than in the United States or an effect of time, as 6 years had elapsed since the US studies were published when we carried out our study.

The rates of denial of health insurance benefits in the US studies were 11%[3] and 12%,[7] compared with 5% for the cured cancer patients in our study. This difference may reflect the fact that in Canada, where there is universal health insurance, private insurance companies that offer only supplementary benefits may not be as selective as in the United States.

It has been reported that most cancer patients who work can satisfactorily carry out their work-related tasks.[8,9] Most of the cured cancer patients (79%) but only 50% of the poor prognosis subjects in our study felt that they were as capable of working as they had been before their illness.

Our results suggest that in Montreal cured cancer patients do not encounter more discrimination in the work force than do people who have never had cancer. As shown by matched analysis, discrimination did not differ significantly between the cured cancer patients and the control subjects. These findings are supported by the fact that the cured patients cited discrimination as the least

Table V—Matched analysis of 101 cured–control pairs

Variable	Odds ratio (and 95% confidence limits [CL])	p
Willingness to reveal medical history to prospective employer if asked	1.2 (0.47, 5.25)	0.407
Denial of standard work benefits	0.4 (0.22, 2.70)	0.344
Discrimination by employer	1.3 (0.56, 2.23)	0.279

Table VI—Matched analysis of 24 cured–poor prognosis pairs

Variable	Odds ratio (and 95% CL)	p
Willingness to reveal medical history to prospective employer if asked	0.0 (0.0, 0.64)	0.008
Denial of standard work benefits	0.2 (0.01, 1.70)	0.20
Discrimination by employer	2.0 (0.33, 10.16)	0.69

important problem faced by cancer patients returning to work.

Comparisons between the cured cancer patients and the cancer patients with a poor prognosis indicated that discrimination in the work force did not differ significantly between the two groups. The only statistically significant difference was in willingness to reveal one's cancer history to a prospective employer if asked: all the patients in the poor prognosis group said they would divulge their cancer history, compared with one third of the cured patients. A possible explanation for this difference is that cured cancer patients, who are no longer affected by the disease, perceive the disease differently than do patients with a poor prognosis, who are still affected by it. Alternatively, cured cancer patients may prefer not to divulge their cancer history out of fear of discrimination. Those with a poor prognosis, on the other hand, may find it necessary to reveal their medical history since they may feel or look ill and be undergoing treatment that would require frequent absences from work. Both groups may prefer to hide their cancer history to protect themselves from possible discrimination, but those with a poor prognosis may recognize that because of their active disease they have no choice but to reveal their cancer history. The comparisons with the poor prognosis group should be interpreted cautiously in view of the small sample.

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Meetings

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July

July 12-15, 1987

International Symposium and Workshop on Verocytotoxin-Producing *Escherichia coli* Infections
Westin Hotel, Toronto
Ms. Sandra Leith, administrative coordinator, Continuing Education, Faculty of Medicine, Medical Sciences Building, University of Toronto, Toronto, Ont. M5S 1A8; (416) 978-2718

July 13-15, 1987

International Symposium on Occupational Asthma
Hyatt Regency Hotel, Vancouver
Secretariat, 801-750 Jervis St., Vancouver, BC V6E 2A9; (604) 681-5226

July 19-22, 1987

The Foundations of Management, Physician Manager Institute
Rodd's Mill River Resort, Woodstock, PEI
Mr. Chuck Shields, Canadian College of Health Service Executives, 201-17 York St., Ottawa, Ont. K1N 5S7, (613) 235-7218, or Mr. Joe Chouinard, Canadian Medical Association, PO Box 8650, Ottawa, Ont. K1G 0G8, (613) 731-9331

July 23-25, 1987

Leadership Skills Development, Physician Manager Institute
Rodd's Mill River Resort, Woodstock, PEI
Mr. Chuck Shields, Canadian College of Health Service Executives, 201-17 York St., Ottawa, Ont. K1N 5S7, (613) 235-7218, or Mr. Joe Chouinard, Canadian Medical Association, PO Box 8650, Ottawa, Ont. K1G 0G8, (613) 731-9331

August

August 2-5, 1987

The Uremic Diabetic: a Status Report. Satellite Symposium to the 10th International Congress of Nephrology
Jerusalem
Mrs. Daliah Raif or Mrs. Maria Rudnick, convention coordinators, Dymark D.I.T. Travel Inc., 1-3761 Victoria Park Ave., Scarborough, Ont. M1W 3S2; (416) 492-8291 (1-800-387-5072)

Aug. 26, 1987

Annual Meeting of the Canadian Medical Protective Association
Prince Edward Hotel, Charlottetown
Mrs. Beverley Allen, executive assistant, Canadian Medical Protective Association, PO Box 8225, Ottawa, Ont. K1G 3H7; (613) 236-2100